

Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy

ABSTRACT

Professionals should reexamine negative assumptions about the quality of life with prenatally detectable impairments and should reform clinical practice and public policy to improve informed decision making and genuine reproductive choice. Current data on children and families affected by disabilities indicate that disability does not preclude a satisfying life. Many problems attributed to the existence of a disability actually stem from inadequate social arrangements that public health professionals should work to change.

This article assumes a pro-choice perspective but suggests that unreflective uses of prenatal testing could diminish, rather than expand, women's choices. This critique challenges the view of disability that lies behind the social endorsement of such testing and the conviction that women will or should end their pregnancies if they discover that the fetus has a disabling trait. (*Am J Public Health*. 1999;89:1649-1657)

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Although sex selection might ameliorate the situation of some individuals, it lowers the status of women in general and only perpetuates the situation that gave rise to it. . . . If we believe that sexual equality is necessary for a just society, then we should oppose sex selection.

Wertz and Fletcher¹(pp242-243)

The very motivation for seeking an "origin" of homosexuality reveals homophobia. Moreover, such research may lead to prenatal tests that claim to predict for homosexuality. For homosexual people who live in countries with no legal protections these dangers are particularly serious.

Schuklenk et al.²(p6)

The tenor of the preceding statements may spark relatively little comment in the world of health policy, the medical profession, or the readers of this journal, because many recognize the dangers of using the technology of prenatal testing followed by selective abortion for the characteristic of fetal sex. Similarly, the medical and psychiatric professions, and the world of public health, have aided in the civil rights struggle of gays and lesbians by insisting that homosexuality is not a disease. Consequently, many readers would concur with those who question the motives behind searching for the causes of homosexuality that might lead scientists to develop a prenatal test for that characteristic. Many in our society, however, have no such misgivings about prenatal testing for characteristics regarded as genetic or chromosomal diseases, abnormalities, or disabilities:

Human mating that proceeds without the use of genetic data about the risks of transmitting diseases will produce greater mortality and medical costs than if carriers of potentially deleterious genes are alerted to their carrier status and *encouraged* to mate with non-carriers or to use other reproductive strategies [emphasis added].³(p84)

Attitudes toward congenital disability per se have not changed markedly. Both premodern as well as contemporary societies have regarded disability as undesirable and to be avoided. Not only have parents recognized

the birth of a disabled child as a potentially divisive, destructive force in the family unit, but the larger society has seen disability as unfortunate (p 89). . . . Our society still does not countenance the elimination of diseased/disabled people; but it does urge the termination of diseased/disabled fetuses. The urging is not explicit, but implicit (p 90).⁴

Writing in the *American Journal of Human Genetics* about screening programs for cystic fibrosis, A. L. Beaudet acknowledged the tension between the goals of enhancing reproductive choice and preventing the births of children who would have disabilities:

Although some would argue that the success of the program should be judged solely by the effectiveness of the educational programs (i.e., whether screenees understood the information), it is clear that prevention of [cystic fibrosis] is also, at some level, a measure of a screening program, since few would advocate expanding the substantial resources involved if very few families wish to avoid the disease.⁵(p603)

Prenatal tests designed to detect the condition of the fetus include ultrasound, maternal serum α -fetoprotein screening, chorionic villus sampling, and amniocentesis. Some (ultrasound screenings) are routinely performed regardless of the mother's age and provide information that she may use to guide her care throughout pregnancy; others, such as chorionic villus sampling or amniocentesis, do not influence the woman's care during pregnancy but provide information intended to help her decide whether to

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Note. Except where specifically cited in text and in note 58, this article represents the views of the author and not those of the Hastings Center Project on Prenatal Testing for Genetic Disability or its other participants.

continue the pregnancy if fetal impairment is detected. Amniocentesis, the test that detects the greatest variety of fetal impairments, is typically offered to women who will be 35 years or older at the time they are due to deliver, but recently commentators have urged that the age threshold be removed and that the test be available to women regardless of age.⁶ Such testing is increasingly considered a standard component of prenatal care for women whose insurance covers these procedures, including women using publicly financed clinics in some jurisdictions.

These tests, which are widely accepted in the field of bioethics and by clinicians, public health professionals, and the general public, have nonetheless occasioned some apprehension and concern among students of women's reproductive experiences, who find that women do not uniformly welcome the expectation that they will undergo prenatal testing or the prospect of making decisions depending on the test results.⁷ Less often discussed by clinicians is the view, expressed by a growing number of individuals, that the technology is itself based on erroneous assumptions about the adverse impact of disability on life. Argument from this perspective focuses on what is communicated about societal and familial acceptance of diversity in general and disability in particular.⁸⁻¹⁷ Like other women-centered critiques of prenatal testing, this article assumes a pro-choice perspective but suggests that unreflective uses of testing could diminish, rather than expand, women's choices. Like critiques stemming from concerns about the continued acceptance of human differences within the society and the family, this critique challenges the view of disability that lies behind social endorsement of such testing and the conviction that women will, or should, end their pregnancies if they discover that the fetus has a disabling trait.

If public health frowns on efforts to select for or against girls or boys and would oppose future efforts to select for or against those who would have a particular sexual orientation, but promotes people's efforts to avoid having children who would have disabilities, it is because medicine and public health view disability as extremely different from and worse than these other forms of human variation. At first blush this view may strike one as self-evident. To challenge it might even appear to be questioning our professional mission. Characteristics such as chronic illnesses and disabilities (discussed together throughout this article) do not resemble traits such as sex, sexual orientation, or race, because the latter are not in themselves perceived as inimical to a rewarding life. Disability is thought to be just that—

to be incompatible with life satisfaction. When public health considers matters of sex, sexual orientation, or race, it examines how factors in social and economic life pose obstacles to health and to health care, and it champions actions to improve the well-being of those disadvantaged by the discrimination that attends minority status. By contrast, public health fights to eradicate disease and disability or to treat, ameliorate, or cure these when they occur. For medicine and public health, disease and disability is the problem to solve, and so it appears natural to use prenatal testing and abortion as one more means of minimizing the incidence of disability.

In the remainder of this article I argue, first, that most of the problems associated with having a disability stem from discriminatory social arrangements that are changeable, just as much of what has in the past made the lives of women or gays difficult has been the set of social arrangements they have faced (and which they have begun to dismantle). After discussing ways in which the characteristic of disability resembles and differs from other characteristics, I discuss why I believe the technology of prenatal testing followed by selective abortion is unique among means of preventing or ameliorating disability, and why it offends many people who are untroubled by other disease prevention and health promotion activities. I conclude by recommending ways in which health practitioners and policymakers could offer this technology so that it promotes genuine reproductive choice and helps families and society to flourish.

Contrasting Medical and Social Paradigms of Disability

The definitions of terms such as "health," "normality," and "disability" are not clear, objective, and universal across time and place. Individual physical characteristics are evaluated with reference to a standard of normality, health, and what some commentators term "species-typical functioning."^{18,19} These commentators point out that within a society at a particular time, there is a shared perception of what is typical physical functioning and role performance for a girl or boy, woman or man. Boorse's definition of an undesirable departure from species-typicality focuses on the functioning of the person rather than the cause of the problem: "[A] condition of a part or process in an organism is pathological when the ability of the part or process to perform one or more of its species-typical biological functions falls below some central range of the statistical distribution for that ability."^{18(p370)} Daniels writes, "Impairments of normal

species functioning reduce the range of opportunity open to the individual in which he may construct his plan of life or conception of the good."^{19(p27)}

Chronic illness, traumatic injury, and congenital disability may indeed occasion departures from "species-typical functioning," and thus these conditions do constitute differences from both a statistical average and a desired norm of well-being. Certainly society prizes some characteristics, such as intelligence, athleticism, and musical or artistic skill, and rewards people with more than the statistical norm of these attributes; I will return to this point later. Norms on many health-related attributes change over time; as the life span for people in the United States and Canada increases, conditions that often lead to death before 40 years of age (e.g., cystic fibrosis) may become even more dreaded than they are today. The expectation that males will be taller than females and that adults will stand more than 5 feet in height leads to a perception that departures from these norms are not only unusual but undesirable and unhealthy. Not surprisingly, professionals who have committed themselves to preventing illness and injury, or to ameliorating and curing people of illnesses and injuries, are especially attuned to the problems and hardships that affect the lives of their patients. Such professionals, aware of the physical pain or weakness and the psychological and social disruption caused by acute illness or sudden injury, devote their lives to easing the problems that these events impose.

What many scholars, policymakers, and activists in the area of disability contend is that medically oriented understandings of the impact of disability on life contain 2 erroneous assumptions with serious adverse consequences: first, that the life of a person with a chronic illness or disability is forever disrupted, as one's life might be temporarily disrupted as a result of a back spasm, an episode of pneumonia, or a broken leg; second, that if a disabled person experiences isolation, powerlessness, unemployment, poverty, or low social status, these are inevitable consequences of biological limitation. Body, psyche, and social life do change immediately following an occurrence of disease, accident, or injury, and medicine, public health, and bioethics all correctly appreciate the psychological and physical vulnerability of patients and their families and friends during immediate medical crises. These professions fail people with disabilities, however, by concluding that because there may never be full physical recovery, there is never a regrouping of physical, cognitive, and psychological resources with which to participate in a rewarding life. Chronic illness and disability are not equivalent to acute illness or sudden injury, in which an active disease

process or unexpected change in physical function disrupts life's routines. Most people with conditions such as spina bifida, achondroplasia, Down syndrome, and many other mobility and sensory impairments perceive themselves as healthy, not sick, and describe their conditions as givens of their lives—the equipment with which they meet the world. The same is true for people with chronic conditions such as cystic fibrosis, diabetes, hemophilia, and muscular dystrophy. These conditions include intermittent flare-ups requiring medical care and adjustments in daily living, but they do not render the person as unhealthy as most of the public—and members of the health profession—imagine.

People with disabilities are thinking about a traffic jam, a disagreement with a friend, which movie to attend, or which team will win the World Series—not just about their diagnosis. Having a disability can intrude into a person's consciousness if events bring it to the fore: if 2 lift-equipped buses in a row fail to stop for a man using a wheelchair; if the theater ticket agent insults a patron with Down syndrome by refusing to take money for her ticket; if a hearing-impaired person misses a train connection because he did not know that a track change had been announced.

The second way in which medicine, bioethics, and public health typically err is in viewing all problems that occur to people with disabilities as attributable to the condition itself, rather than to external factors. When ethicists, public health professionals, and policymakers discuss the importance of health care, urge accident prevention, or promote healthy lifestyles, they do so because they perceive a certain level of health not only as intrinsically desirable but as a prerequisite for an acceptable life. One commentator describes such a consensual view of types of life in terms of a “normal opportunity range”: “The normal opportunity range for a given society is the array of life plans reasonable persons in it are likely to construct for themselves.”^{19(p33)} Health care includes that which is intended to “maintain, restore, or provide functional equivalents where possible, to normal species functioning.”^{19(p32)}

The paradigm of medicine concludes that the gaps in education, employment, and income that persist between adults with disabilities and those without disabilities are inevitable because the impairment precludes study or limits work. The alternative paradigm, which views people with disabilities in social, minority-group terms, examines how societal arrangements—rules, laws, means of communication, characteristics of buildings and transit systems, the typical 8-hour workday—exclude some people from participating in school,

work, civic, or social life. This newer paradigm is expressed by enactment of the Individuals with Disabilities Education Act and the Americans with Disabilities Act and is behind the drive to ensure that employed disabled people will keep their access to health care through Medicaid or Medicare. This paradigm—still more accepted by people outside medicine, public health, and bioethics than by those within these fields—questions whether there is an inevitable, unmodifiable gap between people with disabilities and people without disabilities. Learning that in 1999, nine years after the passage of laws to end employment discrimination, millions of people with disabilities are still out of the work force, despite their readiness to work²⁰; the social paradigm asks what remaining institutional factors bar people from the goal of productive work. Ethical and policy questions arise in regard to the connection that does or should exist between health and the range of opportunities open to people in the population.

Commitments to alleviate the difficulties arising from chronic illness and disability and efforts to promote healthy lifestyles throughout the population need not lead to a devaluation of the members of society who do not meet our typical understanding of health, but people with disabilities have indeed been subject to systematic segregation and second-class treatment in all areas of life. It is possible to appreciate the norm of 2 arms without being repelled by a woman with 1 arm; yet social science, autobiography, legislation, and case law reveal that people with both visible and “invisible” disabilities lose opportunities to study, work, live where and with whom they choose, attend religious services, and even vote.^{21–27}

The Americans with Disabilities Act, signed into law in 1990, is a ringing indictment of the nation's history with regard to people with disabilities:

Congress finds that . . . (3) discrimination against individuals with disabilities persists in such critical areas as employment, . . . education, recreation, . . . health services, . . . and access to public services; (7) individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society.²⁸

Eight years after the passage of the Americans with Disabilities Act, disabled people reported some improvements in access to public facilities and that things are

getting better in some areas of life, but major gaps between the disabled and the nondisabled still exist in income, employment, and social participation. To dramatically underscore the prevalence of social stigma and discrimination: “fewer than half (45%) of adults with disabilities say that people generally treat them as an equal after they learn they have a disability.”²⁰

It is estimated that 54 million people in the United States have disabilities, of which impairments of mobility, hearing, vision, and learning; arthritis; cystic fibrosis; diabetes; heart conditions; and back problems are some of the most well-known.²⁰ Thus, in discussing discrimination, stigma, and unequal treatment for people with disabilities, we are considering a population that is larger than the known gay and lesbian population or the African American population. These numbers take on new significance when we assess the rationale behind prenatal diagnosis and selective abortion as a desirable strategy to deal with disability.

Prenatal Diagnosis for Disability Prevention

If some forms of disability prevention are legitimate medical and public health activities, and if people with disabilities use the health system to improve and maintain their own health, there is an acknowledgment that the characteristic of disability may not be desirable. Although many within the disability rights movement challenge prenatal diagnosis as a means of disability prevention, no one objects to public health efforts to clean up the environment, encourage seat-belt use, reduce tobacco and alcohol consumption, and provide prenatal care to all pregnant women. All these activities deal with the health of existing human beings (or fetuses expected to come to term) and seek to ensure their well-being. What differentiates prenatal testing followed by abortion from other forms of disability prevention and medical treatment is that prenatal testing followed by abortion is intended not to prevent the disability or illness of a born or future human being but to prevent the birth of a human being who will have one of these undesired characteristics. In reminding proponents of the Human Genome Project that gene therapy will not soon be able to cure disability, James Watson declared,

[W]e place most of our hopes for genetics on the use of antenatal diagnostic procedures, which increasingly will let us know whether a fetus is carrying a mutant gene that will seriously proscribe its eventual development into a functional human being. By terminating such pregnancies, the threat of horrific disease genes contributing to blight

many family's prospects for future success can be erased.^{29(p19)}

But Watson errs in assuming that tragedy is inevitable for the child or for the family. When physicians, public health experts, and bioethicists promote prenatal diagnosis to prevent future disability, they let disability become the only relevant characteristic and suggest that it is such a problematic characteristic that people eagerly awaiting a new baby should terminate the pregnancy and "try again" for a healthy child. Professionals fail to recognize that along with whatever impairment may be diagnosed come all the characteristics of any other future child. The health professions suggest that once a prospective parent knows of the likely disability of a future child, there is nothing else to know or imagine about who the child might become: disability subverts parental dreams.

The focus of my concern here is not on the decision made by the pregnant woman or by the woman and her partner. I focus on the view of life with disability that is communicated by society's efforts to develop prenatal testing and urge it on every pregnant woman. If public health espouses goals of social justice and equality for people with disabilities, as it has worked to improve the status of women, gays and lesbians, and members of racial and ethnic minorities, it should reconsider whether it wishes to continue endorsing the technology of prenatal diagnosis. If there is an unshakable commitment to the technology in the name of reproductive choice, public health should work with practitioners to change the way in which information about impairments detected in the fetus is delivered.

Rationales for Prenatal Testing

The medical professions justify prenatal diagnosis and selective abortion on the grounds of the costs of childhood disability—the costs to the child, to the family, and to the society. Some proponents of the Human Genome Project from the fields of science and bioethics argue that in a world of limited resources, we can reduce disability-related expenditures if all diagnoses of fetal impairment are followed by abortion.³⁰

On both empirical and moral grounds, endorsing prenatal diagnosis for societal reasons is dangerous. Only a small fraction of total disability can now be detected prenatally, and even if future technology enables the detection of predisposition to diabetes, forms of depression, Alzheimer disease, heart disease, arthritis, or back problems—all more prevalent in the population than many of the currently detectable conditions—we will never manage to detect and prevent most disability. Rates of disability increase markedly

with age, and the gains in life span guarantee that most people will deal with disability in themselves or someone close to them. Laws and services to support people with disabilities will still be necessary, unless society chooses a campaign of eliminating disabled people in addition to preventing the births of those who would be disabled. Thus, there is small cost-saving in money or in human resources to be achieved by even the vigorous determination to test every pregnant woman and abort every fetus found to exhibit disabling traits.

My moral opposition to prenatal testing and selective abortion flows from the conviction that life with disability is worthwhile and the belief that a just society must appreciate and nurture the lives of all people, whatever the endowments they receive in the natural lottery. I hold these beliefs because—as I show throughout this article—there is abundant evidence that people with disabilities can thrive even in this less than welcoming society. Moreover, people with disabilities do not merely take from others, they contribute as well—to families, to friends, to the economy. They contribute neither in spite of nor because of their disabilities, but because along with their disabilities come other characteristics of personality, talent, and humanity that render people with disabilities full members of the human and moral community.

Implications for People With Disabilities

Implications for children and adults with disabilities, and for their families, warrant more consideration. Several prominent bioethicists claim that to knowingly bring into the world a child who will live with an impairment (whether it be a "withered arm," cystic fibrosis, deafness, or Down syndrome) is unfair to the child because it deprives the child of the "right to an open future" by limiting some options.³¹ Green's words represent a significant strand of professional thinking: "In the absence of adequate justifying reasons, a child is morally wronged when he/she is knowingly, deliberately, or negligently brought into being with a health status likely to result in significantly greater disability or suffering, or significantly reduced life options relative to the other children with whom he/she will grow up."^{32(p10)} Green is not alone in his view that it is irresponsible to bring a child into the world with a disability.^{33,34}

The biology of disability can affect people's lives, and not every feature of life with a disability is socially determined or mediated. People with cystic fibrosis cannot now expect to live to age 70. People with type I diabetes

can expect to have to use insulin and to have to think carefully and continuously about what and how much they eat and about their rest and exercise, perhaps more than typical sedentary people who are casual about the nutritional content of their food. People who use a wheelchair for mobility will not climb mountains; people with the intellectual disabilities of Down syndrome or fragile X chromosome are not likely to read this article and engage in debate about its merits and shortcomings. Yet, as disability scholars point out, such limitations do not preclude a whole class of experiences, but only certain instances in which these experiences might occur. People who move through the world in wheelchairs may not be able to climb mountains, but they can and do participate in other athletic activities that are challenging and exhilarating and call for stamina, alertness, and teamwork. Similarly, people who have Down syndrome or fragile X chromosome are able to have other experiences of thinking hard about important questions and making distinctions and decisions. Thus, they exercise capacities for reflection and judgment, even if not in the rarified world of abstract verbal argument (P. Ferguson [pferguso@oregon.uoregon.edu], e-mail, March 5, 1999).

The child who will have a disability may have fewer options for the so-called open future that philosophers and parents dream of for children. Yet I suspect that disability precludes far fewer life possibilities than members of the bioethics community claim. That many people with disabilities find their lives satisfying has been documented. For example, more than half of people with spinal cord injury (paraplegia) reported feeling more positively about themselves since becoming disabled.^{35(p83)} Similarly, Canadian teenagers who had been extremely-low-birthweight infants were compared with nondisabled teens and found to resemble them in terms of their own subjective ratings of quality of life. "Adolescents who were [extremely-low-birthweight] infants suffer from a greater burden of morbidity, and rate their health-related quality of life as significantly lower than control teenagers. Nevertheless, the vast majority of the [extremely-low-birthweight] respondents view their health-related quality of life as quite satisfactory and are difficult to distinguish from controls."^{36(p453)}

Interestingly, professionals faced with such information often dismiss it and insist that happy disabled people are the exceptions.³⁷ Here again, James Watson expresses a common view when he says,

Is it more likely for such children to fall behind in society or will they through such afflictions develop the strengths of character

and fortitude that lead . . . to the head of their packs? Here I'm afraid that the word handicap cannot escape its true definition—being placed at a disadvantage. From this perspective seeing the bright side of being handicapped is like praising the virtues of extreme poverty. To be sure, there are many individuals who rise out of its inherently degrading states. But we perhaps most realistically should see it as the major origin of asocial behavior."^{29(p19)}

I return to the points made earlier regarding how many of the supposed limits and problems associated with disability are socially, rather than biologically, imposed. The 1998 survey of disabled people in the United States conducted by Louis Harris Associates found gaps in education, employment, income, and social participation between people with disabilities and people without disabilities and noted that fewer disabled than nondisabled people were "extremely satisfied" with their lives. The reasons for dissatisfaction did not stem from anything inherent in the impairments; they stemmed from disparities in attainments and activities that are not inevitable in a society that takes into account the needs of one sixth of its members.²⁰ Only 29% of people with disabilities work full- or part-time, yet of disabled working-age people surveyed who were unemployed, more than 70% would prefer to work, and most did not perceive their disability as precluding them from productive employment. Unemployment, and thus inadequate income, coupled with problems in obtaining health insurance or in having that insurance pay for actual disability-related expenses, accounts for the problems most commonly described by disabled people as diminishing life satisfaction.²⁰

For children whose disabling conditions do not cause early degeneration, intractable pain, and early death, life offers a host of interactions with the physical and social world in which people can be involved to their and others' satisfaction. Autobiographical writings and family narratives testify eloquently to the rich lives and the even richer futures that are possible for people with disabilities today^{22,38} (also P. Ferguson [pferguso@oregon.uoregon.edu], e-mail, March 5, 1999).

Nonetheless, I do not deny that disability can entail physical pain, psychic anguish, and social isolation—even if much of the psychological and social pain can be attributed to human cruelty rather than to biological givens. In order to imagine bringing a child with a disability into the world when abortion is possible, prospective parents must be able to imagine saying to a child, "I wanted you enough and believed enough in who you could be that I felt you could have a life you would appreciate even with the difficulties your dis-

ability causes." If parents and siblings, family members and friends can genuinely love and enjoy the child for who he or she is and not lament what he or she is not; if child care centers, schools, and youth groups routinely include disabled children; if television programs, children's books, and toys take children with disabilities into account by including them naturally in programs and products, the child may not live with the anguish and isolation that have marred life for generations of disabled children.

Implications for Family Life

Many who are willing to concede that people with disabilities could have lives they themselves would enjoy nonetheless argue that the cost to families of raising them justifies abortion. Women are seen to carry the greatest load for the least return in caring for such a child. Proponents of using the technology to avoid the births of children with disabilities insist that the disabled child epitomizes what women have fought to change about their lives as mothers: unending labor, the sacrifice of their work and other adult interests, loss of time and attention for the other children in the family as they juggle resources to give this disabled child the best available support, and uncertain recompense in terms of the mother's relationship with the child.³⁹

Writing in 1995 on justifications for prenatal testing, Botkin proposed that only conditions that impose "burdens" on parents equivalent to those of an unwanted child warrant society-supported testing.

The parent's harms are different in many respects from the child's, but include emotional pain and suffering, loss of a child, loss of opportunities, loss of freedom, isolation, loneliness, fear, guilt, stigmatization, and financial expenses. . . . Some conditions that are often considered severe may not be associated with any experience of harm for the child. Down syndrome is a prime example. Parents in this circumstance are not harmed by the suffering of a child . . . but rather by their time, efforts, and expenses to support the special needs of an individual with Down syndrome. . . . It might also be added that parents are harmed by their unfulfilled expectations with the birth of an impaired child. In general terms, the claim is that parents suffer a sufficient harm to justify prenatal testing or screening when the severity of a child's condition raises problems for the parents of a similar magnitude to the birth of an unwanted child. . . . [P]arents of a child with unwanted disability have their interests impinged upon by the efforts, time, emotional burdens, and expenses added by the disability that they would not have otherwise experienced with the birth of a healthy child.^{40(pp36-37)}

I believe the characterizations found in the writings of Wertz and Fletcher³⁹ and Botkin⁴⁰ are at the heart of professionals' support for prenatal testing and deserve careful scrutiny. Neither Wertz and Fletcher nor Botkin offer citations to literature to support their claims of family burden, changed lifestyle, disappointed expectations, or additional expenses, perhaps because they believe these are indisputable. Evaluating the claims, however, requires recognizing an assumption implied in them: that there is no benefit to offset the "burden," in the way that parents can expect rewards of many kinds in their relationship with children who do not have disabilities. This assumption, which permeates much of the medical, social science, and bioethics literature on disability and family life and disability in general, rests on a mistaken notion. As rehabilitation psychologist Beatrice Wright has long maintained,^{41,42} people imagine that incapacity in one arena spreads to incapacity in all—the child with cystic fibrosis is always sick and can never play; the child who cannot walk cannot join classmates in word games, parties, or sleepovers; someone who is blind is also unable to hear or speak. Someone who needs assistance with one activity is perceived to need assistance in all areas and to contribute nothing to the social, emotional, or instrumental aspects of family life.

Assuming for a moment that there are "extra burdens" associated with certain aspects of raising children with disabilities, consider the "extra burdens" associated with raising other children: those with extraordinary (above statistical norm) aptitude for athletics, art, music, or mathematics. In a book on gifted children, Ellen Winner writes,

[A]ll the family's energy becomes focused on this child. . . . Families focus in two ways on the gifted child's development: either one or both parents spend a great deal of time stimulating and teaching the child themselves, or parents make sacrifices so that the child gets high-level training from the best available teachers. In both cases, family life is totally arranged around the child's needs. Parents channel their interests into their child's talent area and become enormously invested in their child's progress.^{43(p187)}

Parents, professionals working with the family, and the larger society all value the gift of the violin prodigy, the talent of the future Olympic figure skater, the aptitude of a child who excels in science and who might one day discover the cure for cancer. They perceive that all the extra work and rearrangement associated with raising such children will provide what people seek in parenthood: the opportunity to give ourselves to a new being who starts out with the

best we can give, who will enrich us, gladden others, contribute to the world, and make us proud.

If professionals and parents believed that children with disabilities could indeed provide their parents many of the same satisfactions as any other child in terms of stimulation, love, companionship, pride, and pleasure in influencing the growth and development of another, they might reexamine their belief that in psychological, material, and social terms, the burdens of raising disabled children outweigh the benefits. A vast array of literature, both parental narrative and social science quantitative and qualitative research, powerfully testifies to the rewards—typical and atypical—of raising children with many of the conditions for which prenatal testing is considered de rigeur and abortion is expected (Down syndrome, hemophilia, cystic fibrosis, to name only some).⁴⁴⁻⁵⁰ Yet bioethics, public health, and genetics remain woefully—scandalously—oblivious, ignorant, or dismissive of any information that challenges the conviction that disability dooms families.

Two years before the gene mutation responsible for much cystic fibrosis was identified, Walker et al. published their findings about the effects of cystic fibrosis on family life. They found that mothers of children with cystic fibrosis did not differ from mothers of children without the condition on measures of

. . . Child Dependency and Management Difficulty, Limits on Family Opportunity, Family Disharmony, and Financial Stress. The difference between the two groups of mothers almost reached statistical significance on a fifth subscale, Personal Burden, which measured the mother's feeling of burden in her caretaking role. . . . The similarities between mothers of children with cystic fibrosis and those with healthy children were more apparent than the differences. Mothers of children with cystic fibrosis did not report significantly higher levels of stress than did the control group mothers of healthy children. Contrary to suggestions that mothers of children with cystic fibrosis feel guilty and inadequate as parents, the mothers in this study reported levels of parenting competence equal to those reported by the mothers of healthy children.^{50(p242-243)}

The literature on how disability affects family life is, to be sure, replete with discussions of stress; anger at unsupportive members of the helping professions; distress caused by hostility from extended family, neighbors, and strangers; and frustration that many disability-related expenses are not covered by health insurance.⁴⁴⁻⁵¹ And it is a literature that increasingly tries to distinguish why—under what conditions—some families of disabled children founder and others thrive. Contrary to the beliefs still

much abroad in medicine, bioethics, and public health, recent literature does not suggest that, on balance, families raising children who have disabilities experience more stress and disruption than any other family.⁵²

Implications for Professional Practice

Reporting in 1997 on a 5-year study of how families affected by cystic fibrosis and sickle cell anemia viewed genetic testing technologies, Duster and Beeson learned to their surprise that the closer the relationship between the family member and the affected individual, the more uncomfortable the family member was with the technology.

[The] closer people are to someone with genetic disease the more problematic and usually unacceptable genetic testing is as a strategy for dealing with the issues. . . . The experience of emotional closeness to someone with a genetic disease reduces, rather than increases, the acceptability of selective abortion. A close relationship with an affected person appears to make it more difficult to evaluate the meaning or worth of that person's existence solely in terms of their genetic disease. Family members consistently affirm the value of the person's life in spite of the disorders, and see value for their family in their experiences with (and) of this member, and in meeting the challenges the disease poses.^{53(p43)}

This finding is consistent with other reports that parents of children with disabilities generally reject the idea of prenatal testing and abortion of subsequent fetuses, even if those fetuses are found to carry the same disabling trait.^{54,55}

Professionals charged with developing technologies, offering tests, and interpreting results should assess their current assumptions and practice on the basis of the literature on disability and family life generally and data about how such families perceive selective abortion. Of the many implications of such data, the first is that familiarity with disability as one characteristic of a child one loves changes the meaning of disability for parents contemplating a subsequent birth. The disability, instead of being the child's sole, or most salient, characteristic, becomes only one of the child's characteristics, along with appearance, aptitudes, temperament, interests, and quirks. The typical woman or couple discussing prenatal testing and possible pregnancy termination knows very little about the conditions for which testing is available, much less what these conditions might mean for the daily life of the child and the family. People who do not already have a child with a

disability and who are contemplating prenatal testing must learn considerably more than the names of some typical impairments and the odds of their child's having one.

To provide ethical and responsible clinical care for anyone concerned about reproduction, professionals themselves must know far more than they now do about life with disability; they must convey more information, and different information, than they now typically provide. Shown a film about the lives of families raising children with Down syndrome, nurses and genetic counselors—but not parents—described the film as unrealistic and too positive a portrayal of family life.⁵⁶ Whether the clinician is a genetics professional or (as is increasingly the case) an obstetrician promoting prenatal diagnosis as routine care for pregnant women, the tone, timing, and content of the counseling process cry out for drastic overhaul.

Many discussions of genetic counseling suggest that counselors (even graduates of master's-level genetic counseling programs, who now provide a minority of the information that surrounds the testing process and the decisions following results) are ill equipped by their own training and norms of practice to provide any insights into disability in today's society. Most graduate programs in genetic counseling do not include courses in the social implications of life with disability for children and families; do not include contact between counselor trainees and disabled children and adults outside clinical settings; and do not expose counselors to the laws, disability rights organizations, and peer support groups that constitute what is described as the disability rights and independent living movement. Often, if providers seek a "consumer" perspective on genetic issues, they consult the Alliance of Genetic Support Groups. This organization, however, has focused on genetic research and cure and has not concentrated on improving life for people with genetic disabilities; it is not currently allied in activity or ideology with the disabled community and the social paradigm of disability. Reviews of medical school curricula suggest that medical students do not receive formal instruction on life with disability, which would remind them that the people with disabilities they see in their offices have lives outside those offices.

Until their own education is revamped, obstetricians, midwives, nurses, and genetics professionals cannot properly counsel prospective parents. With broader exposure themselves, they would be far more likely to engage in discussions with their patients that would avoid problems such as those noted by Lippmann and Wilfond in a survey of genetic counselors. These researchers found that

counselors provided far more positive information about Down syndrome and cystic fibrosis to parents already raising children diagnosed with those conditions than they did to prospective parents deciding whether to continue pregnancies in which the fetus had been found to have the condition.

At the least, we must recognize that every description of a genetic disorder is a story that contains a message. The story is the vehicle through which complex and voluminous information is reduced for the purposes of communication between health-care provider and health-care seeker. The message is shaped as the storyteller selects what to include and what to exclude to reduce the amount of information. . . . Should we strive to tell the same story to families considering carrier testing and prenatal diagnosis and to families who receive a postnatal diagnosis? . . . Is telling the same story required if we are to provide sufficiently balanced information to allow potential parents to make fully informed family-planning decisions?⁵⁷

Lippman and Wilfond question the disparity in information provided; I call for change to ensure that everyone obtaining testing or seeking information about genetic or prenatally diagnosable disability receives sufficient information about predictable difficulties, supports, and life events associated with a disabling condition to enable them to consider how a child's disability would fit into their own hopes for parenthood. Such information for all prospective parents should include, at a minimum, a detailed description of the biological, cognitive, or psychological impairments associated with specific disabilities, and what those impairments imply for day-to-day functioning; a discussion of the laws governing education, entitlements to family support services, access to buildings and transportation, and financial assistance to disabled children and their families; and literature by family members of disabled children and by disabled people themselves.

If prenatal testing indicates a disabling condition in the fetus, the following disability-specific information should be given to the prospective parents: information about services to benefit children with specific disabilities in a particular area, and about which of these a child and family are likely to need immediately after birth; contact information for a parent-group representative; and contact information for a member of a disability rights group or independent living center. In addition, the parents should be offered a visit with both a child and family and an adult living with the diagnosed disability.

Although some prospective parents will reject some or all of this information and these contacts, responsible practice that is concerned with genuine informed decision making and true reproductive choice must

include access to this information, timed so that prospective parents can assimilate general ideas about life with disability before testing and obtain particular disability-relevant information if they discover that their fetus carries a disabling trait. These ideas may appear unrealistic or unfeasible, but a growing number of diverse voices support similar versions of these reforms to encourage wise decision making. Statements by Little People of America, the National Down Syndrome Congress, the National Institutes of Health workshop, and the Hastings Center Project on Prenatal Testing for Genetic Disability all urge versions of these changes in the process of helping people make childbearing decisions.⁵⁸⁻⁶¹

These proposals may be startling in the context of counseling for genetically transmitted or prenatally diagnosable disability, but they resonate with the recent discussion about childbearing for women infected with the HIV virus:

The primary task of the provider would be to engage the client in a meaningful discussion of the implications of having a child and of not having a child for herself, for the client's family and for the child who would be born. . . . Providers would assist clients in examining what childbearing means to them. . . . Providers also would assist clients in gaining an understanding of the factual information relevant to decisions about childbearing. . . . however, the conversation would cover a range of topics that go far beyond what can be understood as the relevant *medical* facts, and the direction of the conversation would vary depending on each person's life circumstances and priorities [emphasis added].^{62(pp453-454)}

This counseling process for women with HIV who are considering motherhood demonstrates that information in itself is not sufficient. As Mary White, Arthur Caplan, and other commentators on genetic counseling have noted, the norm of nondirectiveness, even when followed, may leave people who are seeking help with difficult decisions feeling bewildered and abandoned.^{63,64} Along with others who have expressed growing concern about needed reforms in the conduct of prenatal testing and counseling, I urge a serious conversation between prospective parents and clinicians about what the parents seek in childrearing and how a disabling condition in general or a specific type of impairment would affect their hopes and expectations for the rewards of parenthood. For some people, any mobility, sensory, cognitive, or health impairment may indeed lead to disappointment of parental hopes; for others, it may be far easier to imagine incorporating disability into family life without believing that the rest of their lives will be blighted.

Ideally, such discussions will include mention of the fact that every child inevitably differs from parental dreams, and that successful parenting requires a mix of shaping and influencing children and ruefully appreciating the ways they pick and choose from what parents offer, sometimes rejecting tastes, activities, or values dear to the parents. If prospective parents cannot envision appreciating the child who will depart in particular, known ways from the parents' fantasy, are they truly ready to raise would-be athletes when they hate sports, classical violinists when they delight in the Grateful Dead? Testing and abortion guarantee little about the child and the life parents create and nurture, and all parents and children will be harmed by inflated notions of what parenting in an age of genetic knowledge can bring in terms of fulfilled expectations.

Public health professionals must do more than they have been doing to change the climate in which prenatal tests are offered. Think about what people would say if prenatal clinics contained pamphlets telling poor women or African American women that they should consider refraining from childbearing because their children could be similarly poor and could endure discrimination or because they could be less healthy and more likely to find themselves imprisoned than members of the middle class or than Whites. Public health is committed to ending such inequities, not to endorsing them, tolerating them, or asking prospective parents to live with them. Yet the current promotion of prenatal testing condones just such an approach to life with disability.

Practitioners and policymakers can increase women's and couples' reproductive choice through testing and counseling, and they can expend energy and resources on changing the society in which families consider raising disabled children. If families that include children with disabilities now spend more money and ingenuity on after-school care for those children because they are denied entrance into existing programs attended by their peers and siblings,⁶⁵ public health can join with others to ensure that existing programs include *all* children. The principle of education for all, which is reforming public education for disabled children, must spread to incorporate those same children into the network of services and supports that parents count on for other children. Such programs, like other institutions, must change to fit the people who exist in the world, not claim that some people should not exist because society is not prepared for them. We can fight to reform insurance practices that deny reimbursement for diabetes test strips; special diets for

people with disabilities; household modifications that give disabled children freedom to explore their environment; and modifications of equipment, games, and toys that enable disabled children to participate in activities comparable to those of their peers. Public health can fight to end the catch-22 that removes subsidies for life-sustaining personal assistance services once disabled people enter the workforce, a policy that acts as a powerful disincentive to productivity and needlessly perpetuates poverty and dependence.

Laws such as the Individuals with Disabilities Education Act and the Americans with Disabilities Act chart a course of inclusion for disabled people of all ages. In 1980, Gliedman and Roth, who pioneered the development of the minority-group paradigm that infuses much of the critique of current genetic technology, wrote a blueprint for the inclusive society that public health should strive to create:

Suppose that somewhere in the world an advanced industrial society genuinely respected the needs and the humanity of handicapped people. What would a visitor from this country make of the position of the disabled individual in American life? . . . To begin with, the traveler would take for granted that a market of millions of children and tens of millions of adults would not be ignored. He would assume that many industries catered to the special needs of the handicapped. Some of these needs would be purely medical . . . but many would not be medical. The visitor would expect to find industries producing everyday household and domestic appliances designed for the use of people with poor motor coordination. . . . He would anticipate a profusion of specialized and sometimes quite simple gadgets designed to enhance control of a handicapped person over his physical world—special hand tools, office supplies, can openers, eating utensils, and the like. . . .

As he examined our newspapers, magazines, journals and books, as he watched our movies, television shows, and went to our theaters, he would look for many reports about handicap, . . . cartoon figures on children's TV programs, and many characters in children's stories who are handicapped. He would expect constantly to come across advertisements aimed at handicapped people. He would expect to find many handicapped people appearing in advertisements not specifically aimed at them.

The traveler would explore our factories, believing that handicapped people were employed in proportion to their vast numbers. . . . He would walk the streets of our towns and cities. And everywhere he went he would expect to see multitudes of handicapped people going about their business, taking a holiday, passing an hour with able-bodied or handicapped friends, or simply being alone. . . .

He would explore our manmade environment, anticipating that provision was made for the handicapped in our cities and towns.

. . . He would expect the tiniest minutiae of our dwellings to reflect the vast numbers of disabled people. . . .

He would assume that disabled individuals had their share of elected and appointive offices. He would expect to find that the role played by the disabled as a special interest group at the local and national levels was fully commensurate with their great numbers.^{66(p13-15)}

Despite the strides of the past few decades, our current society is far from the ideal described by Gliedman and Roth, an ideal toward which the disability community strives. Medicine, bioethics, and public health can put their efforts toward promoting such a society; with such efforts, disability could become nearly as easy to incorporate into the familial and social landscape as the other differences these professions respect and affirm as ordinary parts of the human condition. Given that more than 50 million people in the US population have disabling traits and that prenatal tests may become increasingly available to detect more of them, we are confronting the fact that tests may soon be available for characteristics that we have until now considered inevitable facts of human life, such as heart disease.

In order to make testing and selecting for or against disability consonant with improving life for those who will inevitably be born with or acquire disabilities, our clinical and policy establishments must communicate that it is as acceptable to live with a disability as it is to live without one and that society will support and appreciate everyone with the inevitable variety of traits. We can assure prospective parents that they and their future child will be welcomed whether or not the child has a disability. If that professional message is conveyed, more prospective parents may envision that their lives can be rewarding, whatever the characteristics of the child they are raising. When our professions can envision such communication and the reality of incorporation and appreciation of people with disabilities, prenatal technology can help people to make decisions without implying that only one decision is right. If the child with a disability is not a problem for the world, and the world is not a problem for the child, perhaps we can diminish our desire for prenatal testing and selective abortion and can comfortably welcome and support children of all characteristics.

Acknowledgments

This article benefited from my involvement with the project on Prenatal Testing for Genetic Disability of The Hastings Center. Many thanks go to Betty Wolder Levin for giving me the opportunity to present these views. Daniel Goldstein, Alison MacIntyre, Lili Schwan-Rosenwald, Maggie Starr, Caroline Moon, Deborah Kent, Rosemary Agnew, Simone

Davion, and Taran Jeffries provided invaluable help in several phases of the work on this article under exceptionally difficult circumstances.

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